



Person Centered Planning Person Centered Thinking and Choice

Michael Smull

Support Development Associates

The Learning Community for Person Centered Practices

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We have a once in a generation opportunity
And challenges that could result in settling for
incremental change

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Everybody says they are person centered and use a person centered process.

But do we see the outcomes?



What is the federal government saying?



Person Centered Thinking, Planning, and Practice: The Federal Policy Context

Shawn Terrell
Administration for Community Living



Person-Centered Policy

Section 2402(a) of the Affordable Care Act requires the Secretary of Health and Human Services to ensure all states receiving federal funds:

- Develop service systems that are responsive to the needs and choices of beneficiaries receiving home and community-based services (HCBS) and community-based long-term services and supports (LTSS).
- Maximize independence and self-direction.
- Provide support coordination to assist with a community-based supported life.
- Achieve a more consistent and coordinated approach to administration of policies and procedures across programs.



ACA Section 2402(a): Oversight and Assessment of the Administration of Home and Community Based Services

- [Section 2402\(a\) Guidance](#) issued by Secretary Sebelius on June 6, 2014
- Includes HHS-Wide Standards for
 - Person Centered Planning
 - Self-Direction
- **Person Centered Planning and Self Direction** standards must be implemented in all Department of Health and Human Services programs that fund HCBS.

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2402(a) Across HHS

- [CMS HCBS Final Rule](#)
 - [eLTSS ONC Project](#)
- SAMHSA included in AOT Demonstration Program and Certified Community Behavioral Health Clinics
- [ACL Person Centered Counseling Training Program](#): component of the ADRC No Wrong Door grant program.
- Quality
 - [NQF HCBS group](#): PCP will be a significant area for measure development
 - [NIDILRR RRTC on HCBS Outcomes](#)

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Options Counseling vs. Person Centered Counseling

- Options Counseling is a Job Title/Category with practice standards for many people working in a State NWD System.
- Person Centered Counseling is a training program to impart person centered thinking, planning, and practice skills to people working in HCMS systems including Options Counselors and others in the State No Wrong Door System.

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CMS Final Rule Published January 26, 2014- Effective March 17, 2014

Requires a person-centered service plan
for each individual receiving Medicaid
HCBS

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Person Centered Planning: one way to describe it

... is grounded in demonstrating respect for the dignity of all involved...seek to discover, understand and clearly describe the unique characteristics of the person, so that the person:

- Has positive control over the life he/she desires and finds satisfying;
- Is recognized and valued for their contributions to their communities (past, current and potential); and
- Is supported in a web of relationships, both natural and paid, within the desired community/neighborhood

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Person Centered Planning: What is Changing

The Meeting

- Families and the person supported will direct it to the extent they desire
- At a time and location that is convenient for the person
- Will include people they want to attend
- Starts with a round of positive acknowledgement
- Not focused on negatives/fixing/solely addressing what is “wrong”

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Person Centered Planning: What is Changing

- Outcomes and goals are based on the persons preferences and what's important to them.
- How health and well being fits into the desired life – not either/or, but both/and
- Risk Mitigation is clearly described
- Decision making is two fold: substitute judgment, OR supported decision making

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Where the person has others that make decisions

- We are to use “substituted judgement” and “supported decision making”
- We are to ask what would the person want and honor their wishes while accounting for issues of health and safety

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We are to support people in making active choices about:

1. Who provides the services and supports
2. Where the person lives
3. Who they live with
4. What they do with their time (including who to spend it with and employment)
5. What they do with their resources

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And

- We must offer choices
- Goals are to reflect the preferences and desires of the person
- We must account for “risk” and
 - We must document that we are addressing risk in the least restrictive way

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In short the process helps the person make informed choices and the plan reflects those choices.



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The challenge of choice



- It seems simple –
 - Everyone has preferences, likes and dislikes, things they want to be present or absent
- So just
 - Ask people what they want
- Then
 - Help them get it

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But -



- Questions about how you want to live require exploration and reflection. If you have never been asked they are hard to answer
- You may need to try new things to determine what you want
- If you communicate differently, we need to listen differently
- Past trauma impacts expressed choices
- What you want may present a risk we should not support

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And



- Informed choice assumes
 - You know what you want
 - You know what is possible
 - What is possible includes what is desirable
 - You know about any “trade-offs” (e.g. getting this precludes having that)

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And Choice has Boundaries for Everyone

- Imposed by society
 - Laws
 - Expectations/values
- My values
 - What is and is not OK for me and those I trust
- Ripple effect - One choice creates boundaries on other choices
 - My relationships
 - The work I do
 - Where I live
- Resource Driven
 - Financial – how much time or money I have available
- Risk involved

The difference is when the boundaries are set for the convenience of the system and therefore limit choices that meet the person's desires: – operating hours, staff available, policies or procedures.

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The quality of choice versus the quantity



- Quantity doesn't matter if none are desirable
 - Taking a vegetarian to a butcher shop
- Where what someone wants doesn't exist we may be able to develop it
 - But developing new services takes time

Who can make a choice?



- Everyone has preferences and desires and they can be learned

But

- Learning requires skills and learning takes time

And

- With supported decision making everyone can have a voice and a say

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Finally many systems are not structured to support real choice



What is offered is largely determined by -

- What is funded and at what rate
- How it is inspected, licensed, and assessed
- What is encouraged and what is discouraged

And

- Changing where you live and/or what you do is often administratively difficult and therefore informally discouraged

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Underneath the rule

- There is a paradigm change –
 - Going from “we know best” to the person knows best
 - From power over to power with
- For those with surrogate decision makers
 - An expectation of substituted judgement

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Where do we start?

We need skills and tools
that
work for everyone
and
a common language

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What is Important to me

- Be held upright like a big boy
 - Playing with people
- Cooing, smiling, and giggling with others
- Hitting the guys on my playmat and kicking my feet
- Looking out the window, or going outside
 - Tummy time
- Singing songs like head shoulders knees and toes
 - Listening to music
- Baby massage for relaxation
 - Playing with my feet
- Being with my Mommy and Daddy

Zachary (3 months)



What others like
about me

- Great big smile
- Cute laugh
- I give the best hugs
- Big talker
- Always happy
- Cutie Pie
- Mover and a Shaker

How to support/comfort me

- When I am tired I like to chill with my nuk and be held
 - If I get fussy you can rub your hands across the front part of my hair
- Hold me upright and walk around a little, you may pat my back lightly or rub my back
 - Sing to me, or play music, its relaxing
 - Always talk to me- I enjoy having a conversation with you
 - Talk with me and play when you change my diaper
- I will rub my eyes and yawn when I am tired. Sometime my eyes will look red. You can help me nap by holding me and have me use my nuk
- If I am napping and I wake up to early and fuss, please help me by giving me my nuk and rubbing my tummy lightly or running your fingers around the front of my hair. If I still don't go back to sleep, you may need to hold me and rock me.
 - I need a little time to get up from my nap. I may use my nuk.
 - I do pace feeding with a bottle. Burp me and hold me upright after you give me a bottle



This Is Important TO Tyler:

- Tyler likes physical activities such as wrestling with dad or running freely without restrictions
- Enjoys listening to Music – Coming Home by Diddy, Transformer Song New Divide, Trevis Barber Soldier Boy and Show me what I'm Looking For by Carolina Liar
- Going outside to play is great especially on the trampoline
- Loves to watch Music Videos and YouTube – "the others" is the Land Before Time series is dinosaur king.
- Dinosaurs, trains and action figures are some of Tyler's favorite toys
- Tyler loves stuffed dogs
- Tyler is a great eater!
- He likes to be a big boy
- To have friends, to play and entertain others

- 
- Takes away from mom and dad, people who support Tyler best are energetic, happy, loving, caring, and can give him 100% of their time and attention
 - Being well supervised at all times
 - Tell Tyler what he needs to do with minimal words, show him and then let him do it
 - Give Tyler breaks when his legs get tired

Things You Should Know to Best Support Tyler:

Tyler Cannot have MILK

If Tyler's lips begin to swell- Call Mom ASAP on cell phone. Should he be struggling to breathe - immediately call 911

- Sometimes when sitting, Tyler tends to sway side-to-side due to poor core strength and does not like sitting for more than 15 minutes at a time
- Tyler has trouble doing two tasks at once
- Tyler can remove his clothes independently, but requires assistance when putting them on
- If Tyler uses inappropriate words **IGNORE** him
- To make sure he is listening or to get his attention tell him "Quiet Hands" and wait until he claps hands together

In the event of an emergency, until family
[REDACTED] call the following
[REDACTED] sister Tyler.

-254-393-1415 or
254-383-8580 cell
Jessica Ingle -254-247-2962
or 337-447-3446 cell

Hi my name is
TYLER

TYLER SYOBODA IS A SWEET KID WITH AN INFECTIOUS SMILE. HE IS RESILIENT, CARING, AND A PEOPLE LOVER.



IT'S ALL ABOUT ME
Elizabeth Kane

What we love about Elizabeth!
(see pages 4-5 for more info)

- She's a determined self-advocate – ask her about her rally speeches
- A gutsy gal
- Talk about organized!
- A true blue friend
- She lights up a room!
- She's a Fashionista

A Few Things That Are Important TO Me...
(Please see pages 6-10 for more information)

- My independence
- A thriving social life
- Being organized and prepared
- School – Graduation in May 2011!
- Taking good care of myself
- Routines
- Planning for the future – including a job, an apartment, and a boyfriend
- Everything Michael Jackson
- Diet Coke
- Singing at church
- Fun with friends & family
- Writing in my journals
- Avoiding conflict
- Fashion
- Close relationships with Family & Friends

...And A Few Things That Are Important FOR Me:
(Please see pages 11-13 for more information)

- CPap machine, plenty of sleep (may include naps)
- Seizure medications
- Healthy diet and exercise
- Writing in my journals
- Conflict free environments & relationships
- Avoiding a "fireball!"


Here's How You Can Support Me:
(Please see pages 12-14 for more information)

- Help me with time, money, cooking, shopping & some cleaning
- Help me find a job and job training
- Assist me to fix my hair & pick out cute outfits
- Help me make healthy food choices and to exercise
- Understand if I'm upset, I'm probably tired.
- Talk to me nicely & quietly. No bad words.
- When people around me are angry or there is conflict, help me get away
- Help me understand what's going on, what to expect

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Tammy's Description



Tammy's One Page Description

What People Like and Admire about Tammy (Pg 6)

- Is always smiling
- Totally accepts people
- WONDERFUL personality
- Stylish
- Accepting and forgiving
- Resilient
- Great sense of humor
- Friendly and social



What is Important to Tammy (Pg. 7-8)

- Being a part of things
- Having eye contact with everyone
- Looking stylish and having her hair and nails done
- Being comfortable and not having her tubes underneath her
- No roughness in personal care

Supports Tammy Needs to be Happy, Healthy and Safe (Pg. 10-14)

- Always have her head elevated
- To be suctioned frequently (5-6 times per shift). Gurgling noises means she needs to be suctioned
- To have people be kind, sensitive, loving and have a gentle touch
- Be gentle with brushing her hair (she doesn't like it, but wants it to always look nice)
- Always make sure her clothes match and make sure it's not sweat clothes
- Tammy needs to be repositioned every two hours
- Always follow through with a promise or give an explanation of what is going on and when you can keep the promise if something comes up
- Be sure to have Tammy use her body to keep flexible


Tammy's Picture Of A Life (Pg. 19-21)

- Live in a big wheelchair accessible home with extra wide doors, close to her family
- Have a fun and social housemate
- Have a beautician she can go to regularly
- Have a social medical day program close to home
- Have specialized medical services and medical equipment (including backup generator)

~ Sara's One Page Description ~

What People Like and Admire about Sara (Pg 5)

- She has a passion and zest for life
- Friendly and fun
- Positive energy in wanting to advocate for others
- Likes to help and is protective of others
- Very independent
- Knows what she wants to do and is resourceful



What is Important to Sara (Pg. 6-8)


- Being respected and people not breaking their promises
- Being social, joking and doing things with friends
- Making a difference for people
- Being able to smoke without being bugged
- People not messing with her things

Supports Sara Needs to be Happy, Healthy and Safe (Pg. 10-15)

- One person to provide clear directions and expectations
- Give her choices to keep her from getting bored. Always have a "plan B" in case things don't work out
- To be supported unconditionally so she can gain trust in you to help when she moves
- Must have people be consistent with her and talk with her when she get upset or starts self-diagnosing herself
- Have consistent respite for Sara and others to relax and recharge
- ASK Sara to do something, rather than tell her.
- Always follow through with a promise or give an explanation of what is going on and when you can keep the promise if something comes up

Sara's Picture Of A Life (Pg. 20-24)


- Live in a Host Home where she can have her own living space and be able to smoke outside
- Have an active community that has good public transportation and advocacy opportunities
- Have a GED class that can lead to paid work for her
- Have mental health services to support Sara and her new provider



~ Liz's One Page Description ~

What People Like and Admire about Liz

- She knows everyone's birthday
- Has the gift of gab ~ can hold a lengthy conversation with anyone!!
- Has a green thumb and knows lots about plants and flowers
- Never gives up even through long bouts of serious illness
- LOVES animals!
- Her sense of adventure



What is Important to Liz


- Being in control of her life
- Living in her own home with her 3 cats
- Talking with her daughter frequently
- Having lots of information about her health, and any changes in her life
- Being active; doing things with her family and friends
- Staying in touch with friends

Supports Liz Needs to be Content, Healthy and Safe

- When really depressed, family needs to ask "what did you eat today" to help keep an eye on possible malnourishment
- Must be able to keep a small notebook to write notes and help her remember tasks; she will get confused when she is not well or when she is feeling overwhelmed
- When she is not well, it helps if she talks to her daughter every day
- Because of having Fibromyalgia, she needs someone to clean her house regularly for her
- When she isn't well, she needs someone who can grocery shop and run errands for her; or take her to run errands
- A skilled pet sitter to care for pets when Liz is away or unwell

People Who Support Her Best:

- Like to chit chat and are good listeners and processors of information
- Are consistent; punctual and dependable
- Like to share about their own life



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What we have done to address Liz’s malnourishment

What have we Tried	What have we learned	What are we Pleased about	What are we concerned about
<ul style="list-style-type: none">● Healthy frozen meals● Daughter cooking a week’s worth of food for her● High protein shakes 2x a day	<ul style="list-style-type: none">● She doesn’t like processed food● Will almost always eat daughter’s home cooked food● Protein shakes work really well● If she is having a really bad day, might only drink one shake at best	<ul style="list-style-type: none">● She is steadily gaining weight● Found at least two options that work for her● She is committed to eating when she can	<ul style="list-style-type: none">● Stress on daughter to cook and drive 5 hours round trip every weekend● Only eating once a day● Will lose appetite again if depression comes back


+1: Keep doing protein shakes; find someone local to cook occasionally; keep asking “what did you eat today, not just “did you eat today?”



Our friend & colleague: Shelley Dumas

What's Important To Shelley During Her Recovery...

- Avoiding "scary hospital hair" always! Keep hair untangled and unmatted.
- Being included in aspects of her care and plans for her recovery
- Having time to think about things: not having to make a commitment immediately.
- Planning things out after having the time to consider her decisions.
- Being dressed colorfully and comfortably – even if it's a hospital gown!
- Looking good – not in a vain kind of way, but in a stylish, lady-like way.
- Not being bored – she wants things to do and to think about.
- Having her privacy and modesty protected even in the midst of necessary medical procedures.



How You Can Support Shelley During Her Recovery:

- Before you leave the room, make sure she has her "Security System" within reach:
 - IN HER LAP:
 - her cell phone
 - the call light
 - the hospital phone
 - the TV Remote
 - ON THE TABLE TRAY:
 - Hairbrush
 - Hair clips
- Remember she is an expert in supporting other people. She knows a lot and when she doesn't know the answer she knows people who do. Ask for her suggestions about her own care.
- Ask her directly when you have a question. Listen.
- Make sure she has time and assistance to look her best every day.
- Inform her about what you are doing and why. Let her tell you how she'd like it done.
- A sense of humor is always appreciated. Enjoy Shelley's too!

What We Love About Shelley!

She is quick to laugh; she helps us see the fun side of life! She wears really cool jewelry and artful, stylish clothing.

She's a gracious southern lady who can be gracefully direct and straightforward.

She's an amazingly creative problem solver.

Her priorities are clear: Donald, Katherine, Dana & Susan, and the GrandBoys.

She's a very talented tailor and has much expertise in supporting people.


Shelley will crack you up!

She is generous and kind.

She is a Scrabble Shark. Don't let her sweet face fool you!

Shelley's glass is always half full.

~ Ruth's One Page Description (at home)~



What People Like and Admire about Ruth

- Such a "grandmother"
- A true lady
- Has the gift of gab ~ can hold a conversation with anyone!
- Always dressed so nice ~ everything always matches, right down to socks and earrings
- Very liberal thinker for her age

What is Important to Ruth

- Living with granddaughter and grandson-in-law
- Being warm and feeling safe with caregivers
- Having "a little pour" before bed (rum and tea)
- Being a part of whatever is going on at home ~ being in the middle of it!
- Sweets during the day!

Supports Ruth Needs to be Happy, Healthy and Safe

- Needs people to ask frequently if she is warm enough and help her put on sweater/sweatshirt if she is not (she'll be cold when you're not)
- Must have assistance with her medications ~ knows them by color but you need to dole them out and keep track of times
- Needs assistance with bathing and dressing ~ will tell you what clothes she wants to wear for the day/event
- When bathing, no water on face ~ she will wash with cloth
- Must talk with daughter 2-3 times a week on the phone ~ will need you to dial for her
- Must see her doctor right away if she has cough, fever or is "off balance" ~ indications of systemic infection that will grow quickly!


People Who Support her Best

- Like to chit chat
- Are timely and stay busy
- Polite and mannerly
- Have a witty and dry sense of humor
- Can be reassuring and help Ruth feel safe

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~ Neldria's One Page Description ~



What People Like and Admire about "Nell"

- She is gentle
- She loves to talk to people
- She knows about plants and has a room full of beautiful tropical plants (she brings plants back from the dead)
- She tells great stories
- She speaks her mind and speaks up for others

Things that are Important to Nell

- Her lap shawl (she gets chilly)
- Going WHEREVER she wants on her "rascal chair"
- Getting to see people every day
- Talking to daughter, Jennifer, daily
- Her plants (she calls them "the ladies")
- Her friend, Norma (room 117)


Supports Nell needs to be Happy, Healthy and Safe

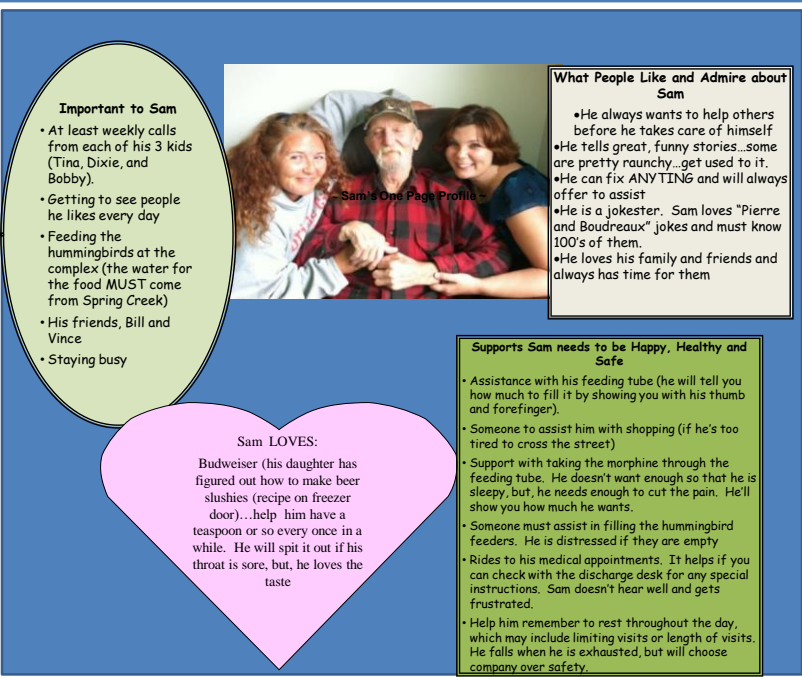
- Assistance with filling her medicine keeper (day minder)...she has difficulty with the lids because she has severe arthritis
- Someone to assist her with weekly shopping (because of her arthritis she needs someone to go along...but she wants to go to the store, too! She can do small runs on her "rascal chair" when she is feeling good.)
- Support in dressing (she does not want to wear adaptive clothing and cannot manage zips, snaps, or buttons). Do not recommend adaptive clothing.
- Someone must assist her in turning her plants ¼ turn a month to make sure they get even light and don't grow crooked...additionally, she often has too much arthritis pain to water the plants and will instruct a helper in how to care for "the ladies"
- She must have assistance with bathing when her arthritis pain is severe, but, she does not need assistance every day. She will let us know when support is desired.
- She may need assistance with things related to crochet, but, on a good day her fingers are flying!
- Ask Nell often if she is in pain...she sometimes lets the pain get overwhelming before she asks for medication (we think she has a high pain threshold as she does generally ask for anything she needs)
- Nell cannot lift her oxygen tank. She will tell you when she needs assistance.

Continuity for Person-Centered Practices 2012

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Important to Sam

- At least weekly calls from each of his 3 kids (Tina, Dixie, and Bobby).
- Getting to see people he likes every day
- Feeding the hummingbirds at the complex (the water for the food MUST come from Spring Creek)
- His friends, Bill and Vince
- Staying busy

Sam's One Page Profile

What People Like and Admire about Sam


- He always wants to help others before he takes care of himself
- He tells great, funny stories...some are pretty raunchy...get used to it.
- He can fix ANYTHING and will always offer to assist
- He is a jokester. Sam loves "Pierre and Boudreaux" jokes and must know 100's of them.
- He loves his family and friends and always has time for them

Sam LOVES:

Budweiser (his daughter has figured out how to make beer slushies (recipe on freezer door)...help him have a teaspoon or so every once in a while. He will spit it out if his throat is sore, but, he loves the taste


Supports Sam needs to be Happy, Healthy and Safe

- Assistance with his feeding tube (he will tell you how much to fill it by showing you with his thumb and forefinger).
- Someone to assist him with shopping (if he's too tired to cross the street)
- Support with taking the morphine through the feeding tube. He doesn't want enough so that he is sleepy, but, he needs enough to cut the pain. He'll show you how much he wants.
- Someone must assist in filling the hummingbird feeders. He is distressed if they are empty
- Rides to his medical appointments. It helps if you can check with the discharge desk for any special instructions. Sam doesn't hear well and gets frustrated.
- Help him remember to rest throughout the day, which may include limiting visits or length of visits. He falls when he is exhausted, but will choose company over safety.



Person Centered Planning results:

- 1.Sam Being listened To: Sam moved to his own apartment, without constant caregiver presence. Friends and family provide transportation and other assistance.
- 2.Less than 2 hours of support per day (with the exceptions of days when he has a chemo treatment and may need a friend or family member to sleep over)
- 3.Focus on his desires and what he is interested in doing (fishing, talking, telling jokes, feeding hummingbirds)



Sam rang the bell at the cancer center on the day of his last chemo treatment. He is joined here in front of the bell by two family members. Sam died peacefully at home later this day. Ginny (pictured in blue) was listening to him tell a story when he passed.



It begins with learning how people want to live their life: What's **Important TO**

What is important **to** a person includes what results in feeling satisfied, content, comforted, fulfilled, and happy.

- Relationships (People to be with)
- Status and control (valued role)
- Rituals & routines (cultural and personal)
- Rhythm or pace of life
- Things to do and places to go (something to look forward to)
- Things to have



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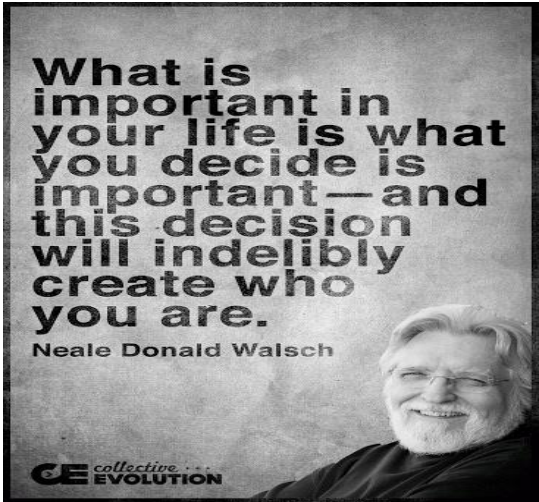
Important TO

- Includes what matters the most to the person – their own definition of quality of life.
- What is important to a person includes only what people “say”:
 - with their words
 - with their behavior
- When words and behavior are in conflict, listen to the behavior.

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A wise man once posted....



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Within that context, **Important FOR** is addressed

What others see as necessary to help the person

- Be valued (social rules, laws)
- Be a contributing member of their community (citizenship)

Issues of health

- Prevention of illness
- Treatment of illness/medical conditions
- Promotion of wellness (diet, exercise, sobriety)

Issues of safety

- Environment
- Well being (physical and emotional)
- Free from fear (threats, abuse)



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Important To and For are Connected

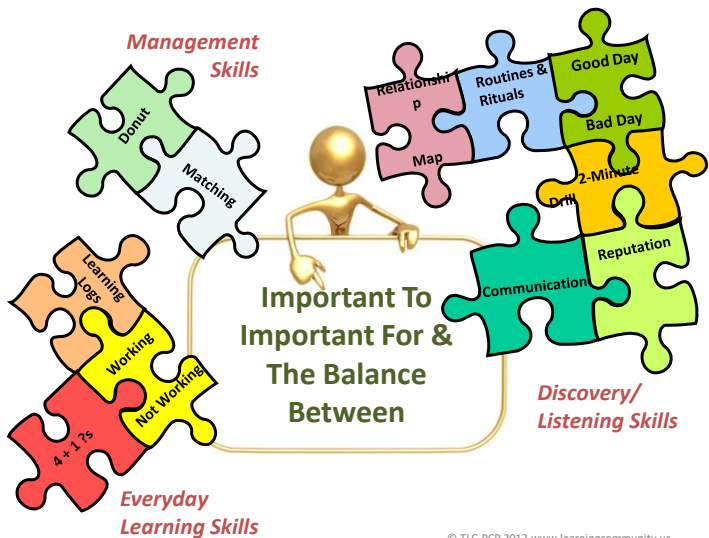
- Important to and important for influence each other
- No one does anything that is “important for” them (willingly) unless a piece of it is “important” to them
- Balance is dynamic (changing) and always involves tradeoffs:
 - Among the things that are “important to”;
 - Between important to and for

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How do we learn and use the learning?

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For more information



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